

Living with cancer challenges: a qualitative analysis of cancer patients' perceptions in Iran

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Received: 4 July 2017 / Accepted: 18 September 2017
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Abstract

Aim Cancer patients are confronted with different challenges. The purpose of current study was to explore Iranian cancer patients' perceptions of these challenges.

Subjects and methods The study took a qualitative approach. Semi-structured interviews were held with 26 cancer patients in four university hospitals in Iran. Transcripts of the interviews underwent conventional content analysis, and categories emerged.

Results The findings came under two major categories: psychological challenges and socio-cultural challenges. Psychological challenges had two subcategories: repressed wishes, and negative feelings. Socio-cultural challenges also had two subcategories: deteriorated relationships and work distress.

Conclusion Findings of the current study have potential to identify psychosocial challenges of cancer patients. These findings propose that psychological support is essential for them. Our results recommend that healthcare providers should work to remain sensitive to cancer patients' challenges. There is a need for culture-based caring programs that are responsive to these patients.

Keywords Cancer · Content analysis · Patient · Challenge

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Introduction

Cancer is considered as one of the most important reasons of death in the world and can happen in all people and in all ethnical, racial, sexual and age groups as well as in all social and economic groups (Silbermann et al. 2015). For more than a decade, cancer incidence rate has been stable in women and it has decreased in men by 2% annually. Moreover, cancer death rate in both sexes has decreased 1.5% annually (Siegel et al. 2017). This disease is recognized as a growing problem in countries of the Middle East and it is predicted that the total number of deaths from cancer will increase 45% up to 2030 (Silbermann et al. 2015). Iran is a country situated in the Middle East. In Iran, cancer is the third cause of death (Seyedfatemi et al. 2014). Sadly, the false cultural beliefs regarding cancer are still present among people, indicating that the cancer taboo has not yet been broken and it remains a taboo subject in Iran; therefore, there is a cultural taboo for cancer in Iran (Mardani-Hamoooleh and Heidari 2017).

Cancer patients are confronted with various issues (Gordon and Chen 2017). They experience considerable unmet needs years after the end of treatment (Keinki et al. 2016). In fact, they usually suffer from challenges in personal functioning, which may last several years past treatment. The failure to counter these challenges correctly leads to greater distress (Lawrence et al. 2017).

Various studies regarding cancer patients' challenges have been documented in different countries. Results of a study in the United States showed that cancer patients experience a wide range of health problems before, during, and after cancer treatment (Westin et al. 2016). Cancer patients in Canada reported persistent health problems and functional restrictions (Ghodraty-Jabloo et al. 2015). A qualitative study in the UK emphasizes the processes leading to a positive or negative adaptation trajectory during early survivorship among cancer

patients (Matheson et al. 2016). Cancer patients in Belgium state very individual symptom experiences and symptom-management styles, which are formed by individual factors such as coping with disease and perceived level of control (Coolbrandt et al. 2016).

Elucidation of cancer challenges will shed light on the terms of providing support to cancer patients regarding these challenges. In this regard, cancer patients usually experience many challenges in Iran but the influence of cancer on the occurrence of these problems remains unclear. In a review of literature, it was found that there are only a few qualitative studies on cancer patients' challenges in the background of Iranian culture. It is therefore suitable to perform a qualitative study in this regard. The aim of this study was to explore the perceptions of Iranian cancer patients about their challenges.

Method

Study design

A qualitative study was conducted. In the present study, the content analysis approach was utilized, which is a shaped coding and categorizing approach that can be used to unobtrusively discover a considerable amount of documented information. Through content analysis, it is possible to distill words into fewer content-related categories (Graneheim and Lundman 2004). In this study, conventional content analysis, which is commonly employed with a study design whose purpose is to describe a phenomenon, was used. It is usually suitable when research information on a phenomenon is limited. Researchers immerse themselves in the data to permit new understandings to appear, which is also described as inductive category development. In this approach, categories are obtained from data during analysis. The significance of the conventional content analysis is that it gains direct data from study participants without imposing prejudiced categories (Graneheim and Lundman 2004).

Study subjects, sampling and settings

Our research was carried out in the cancer wards of four teaching hospitals specializing in the treatment of cancer patients in Tehran and Shahrekord, Iran. The studied hospitals included Shariati (10 patients), Imam Khomeini (5 patients) and Valiasr (4 patients) in Tehran. Also, Khashani hospital (7 patients) in Shahrekord was evaluated. Participants were selected with purposeful methodology. They were recruited from the cancer wards through maximum variation sampling. Twenty-six patients took part in the study of which 15 were females and 11 were males ranging in age from 37 to 58. Nineteen of the patients were married and the rest were single. The participants' level of study ranged from elementary school to

bachelor's level. Regarding the type of cancer, nine persons had breast cancer, seven persons colorectal cancer, five persons had hematologic cancer, three persons had prostate cancer and two persons had lung cancer. The time duration from the diagnosis of cancer was from 2 to 5 years.

Interviews and data collection procedure

The data were collected during the summer and autumn of 2016. Face-to-face semi-structured interviews lasting around 45–55 min were held in suitable quiet locations in the cancer wards. Each patient was interviewed once; thus, 26 interviews were completed over a period of 5 months. The interviews were audio recorded and were implemented in the Persian language. Some parts of the interviews that were relevant to the present article were translated into English by a professional translator and then the English form was converted back into Persian for verification by the second author. The major question asked in the interview was: 'What is your opinion of living with cancer challenges?' Probing questions were also asked to follow the participants' notions and clarify their answers during the interviews such as: "Would you elucidate more regarding this?", "What is the meaning of that idea?", and "Could you please give me an example in order to assist us to suitably comprehend your opinion?"

Data analysis

The data collection and analysis proceeded jointly. When categories had been clarified and data saturation reached, the interviews were finished. Content analysis was utilized to categorize the interview data. The following stages were taken (Graneheim and Lundman 2004):

- The interview transcripts were read several times in order to find a sense of the whole
- The text was separated into condensed meaning units
- The condensed meaning units were abstracted with codes
- The codes were arranged into subcategories and categories, according to evaluations of their similarities and differences
- Categories were generated as explanations of the hidden content of the text.

Trustworthiness was established (Lincoln and Guba 1985). Maximum-variation sampling increased the confirmability and credibility of the data by ensuring its depth and authenticity. We analyzed the findings independently to identify the primary codes and then compared their codes and categories. The credibility of the data was additionally established through member checking and peer checking. A brief of the interviews was returned to the participants, who checked that their opinions were correctly represented. Peer checking was

conducted by the researchers and two doctoral nurses, and found in analogous results.

Ethical considerations

This article is part of research project number 20231 which was approved by Tehran University of Medical Sciences (TUMS), also the ethics committee of TUMS agreed to the study. The data collection was carried out after obtaining a signed informed consent form from the participants. Participants were informed that they had the right to withdraw from the study at any time. They were promised that their reports would be kept confidential.

Results

The results came under two main categories: psychological challenges and socio-cultural challenges. Psychological challenges also had two subcategories—repressed wishes, and negative feelings—as did socio-cultural challenges: deteriorated relationships and work distress. All these categories are detailed in the following subsections.

Psychological challenges

Repressed wishes

The patients experienced a range of repressed wishes after cancer including marriage and continuing education.

“My man of interest left me when he heard I have cancer! Since then, I yearn for it” (participant 4).

“My man of interest left me when he heard I have cancer! Since then, I yearn for it” (participant 4).

“I was studying history and wanted to continue to PhD level but the side effects of treatment decreased my energy, so I dropped out of university” (participant 7).

The patients wanted to be good parents but cancer hindered them.

“Mastectomy prevented me from being an ideal mother for my children and it was aversive to me” (participant 10).

“I wish I could have been a great support for my family but prostatectomy destroyed it” (participant 2).

In fact, patients encountered psychological challenges when they could not fulfill their goals.

“I was a good football player and participating in the world cup was one of my dreams which did not come true because of my disease, leukemia” (participant 14).

“I liked poetry and hoped to publish a collection of my poems but colon cancer lead to discontinuing it” (participant 21).

Briefly, feelings such as fear of death, getting close to the end of life and losing the period of youth was aversive to the patients.

“I feel that my youth has passed me by without experiencing any joy or happiness” (participant 23).

“I always experience negative feelings like fear of death, I feel cancer is the end of life” (participant 11).

Negative feelings

Negative feelings such as frustration, losses in life and feeling inefficient resulted in psychological challenges for the patients.

“Cancer frustrated me in a way that I feel I am a failure and cannot even have children” (participant 18).

“Although prosthesis insertion was done for me, I think mastectomy has deteriorated my effeminacy” (participant 6).

“I feel inefficient and cannot afford anything” (participant 9).

Socio-cultural challenges

Deteriorated relationships

The patients reported some factors including feeling embarrassed to talk about cancer because of the aversive reaction of people which could deteriorate family and social relationships.

“I knew I had cancer but I didn’t tell anyone. People commonly have reactions to cancer patients! For example people point out cancer patients to each other and think they are sentenced to death” (participant 17).

Also, some apparent changes could make the patients ashamed to make relationships with other people.

“Some apparent changes like alopecia make the patient feel embarrassed to have social relationships” (participant 24).

In fact, the patients believed that deterioration in social and family relationships could result in being rejected by society.

“Colon surgery affected my social and family relationships. I tried to stay home and not have relationships with

others. I believe that society rejects cancer patients in our culture” (participant 8).

Cancer surgery is followed by challenges in the sexual and marital relationship which is deeply affected by the culture of the society.

“After mastectomy my husband remarried. In our society men can not accept their wives’ mastectomy and it caused deterioration in the marital relationship” (participant 5).
 “Prostatectomy affected my sexual relationship which led to marital dissatisfaction in my wife. She told me I was no longer a man” (participant 20).

Work distress

Furthermore, one challenge for cancer patients was work distress which is affected by cultural false beliefs.

“If I cannot continue working I will face financial problems. The bosses think that we have a short life so they do not employ us. Unfortunately, people believe that cancer is the end of life” (participant 25).
 “I was fired because of repeated absences. I tried to find another job but the boss asked me why do you want to work since you are going to die soon?!! It seems as if cancer is a stigma” (participant 16).

Reactions of pity from colleagues was counted as a challenge for cancer patients to the extent of their leaving their job.

“I experienced that my co-workers felt sorry for me, which I found intolerable so I left my work. I am jobless now and want to work but I know that this experience will be repeated” (participant 12).

Discussion

On the whole, the results of the present study showed that cancer patients have experienced some socio-cultural and psychological challenges such as repressed wishes and negative feelings. Challenges in marriage, continuing education, parenting and national sports status resulted in a range of repressed wishes and psychological challenges for the patients. Consistent with our results, another study indicated negative psychological effects caused by cancer for the patients in the UK, Belgium and Australia (Matheson et al. 2016; Deckx et al. 2015; Olver et al. 2014). Moreover, another study demonstrated that Syrian women have experienced challenges in marriage and mothering after cancer (Nizamli et al. 2011).

Furthermore, negative feelings intensified psychological challenges for the participants. They mentioned a range of negative feelings which severely affected their life including frustration, inefficiency, anhedonia and fear of death. The findings of similar studies are consistent with our results. The results of a qualitative research in Turkey showed that cancer patients experienced some changes in normal life (Cebeci et al. 2012). In addition, the cancer patients in the UK were concerned about their infertility (Corney and Swinglehurst 2014), while in Taiwan feelings of impairment and death were mentioned (Chen and Chang 2012).

Our participants reported an extensive range of social challenges such as deteriorated relationships and work distress which was deeply affected by cultural factors. Generally, relationships of the participants were deteriorating. Also, cancer patients in the UK experienced social challenges (Matheson et al. 2016). Some factors such as feeling embarrassed to talk about their disease resulted in deterioration in relationships. It seems that cancer is considered a stigma in Iran. Consistent with this, the results of a research demonstrated that the Chinese American cancer patients had experienced cancer as a stigma (Warmoth et al. 2017). Moreover, some apparent changes like alopecia played an important role in deterioration of the patient’s relationships. Also, the results of a similar study in Korea showed that alopecia had caused social distress for the patients and had affected their daily activities (Kim et al. 2012).

On the other hand, the patients reported social exclusion due to cultural issues which would result in social isolation and was similarly experienced by Syrian women with cancer (Nizamli et al. 2011). In addition, sexual relationship of the patients was deteriorated which led to the spouse remarrying and breaking family bonds. The patients reported sexual dissatisfaction after surgery and similar studies in Scotland, Turkey and Syria showed sexual dysfunction in cancer patients (Browne et al. 2011; Akyol et al. 2015; Akkuzu and Ayhan A 2013). However, cultural issues in Iran intensify it—the partners of male patients believed that the man’s gender identity is deteriorated after surgery.

As a whole, work distress such as finding work or returning to work were considered to be social challenges for the patients. The participants suffered from false beliefs in society including short life of cancer patients and being pitied at work, which led them to leaving their jobs. Consistent with this, in Australia the cancer patients were concerned about returning to work (Olver et al. 2014). Also, studies on cancer patients in Nordic countries demonstrated that insufficient work support had reduced their ability to work (Lindbohm et al. 2012). Lack of income was another factor which caused work distress for the patients. The results of a study in Ireland considered low income as a key factor which could cause work distress in cancer patients (Sharp and Timmons 2011). In addition, our participants were expelled because of repeated absences at work which was consistent with the results of a study in

Africa (Bradley and Wilk 2014). Consequently, the results of the present study and similar studies emphasize the importance of work support for cancer patients.

Exploring cultural belief systems not only helps to recognize ways to present more sensitive care to cancer patients from culturally various contexts but also provides valuable lessons to increase the quality of care for them in general. Also, adaptation to the cancer can be complicated for the patients, as it emphasizes the need for psychosocial support. To highlight this need, the health care providers have to prepare to be able to offer such support. In this regard, nurses are eligible and can be effectively trained to manage psychosocial issues among cancer patients.

One strength of our study is that patients were recruited across two provinces from a broad array of hospitals. Also, the results of this research add to the body of knowledge in this field. A limitation of the present study is the homogeneity of the patients related to socio-cultural context. Furthermore, the total number of participants and the nature of the qualitative study restricted the potential to generalize the results.

Conclusion

Results from the present study have key implications for clinical care. Our results recommend that healthcare providers should work to remain sensitive to cancer patients' psychosocial challenges. Also, these findings will facilitate them to develop guidelines and professional practice to support cancer patients. This needs an educated psycho-oncology team that can supervise psychosocial challenges with a multidisciplinary outlook. In addition, further qualitative study is required to more totally comprehend the psychosocial challenges of Iranian cancer patients. Actually, qualitative study that provides profound perception of Iranian patients' psychosocial problems, specifically related to cultural challenges, would provide important understanding.

Acknowledgements The researchers are thankful to all of the patients.

Compliance with Ethical Standards

Conflict of Interests The authors declare that they have no conflict of interests.

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